

Experiences of Growth of Parents of Children with Disabilities: A Qualitative Study

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Abstract

This study explores the lived experiences of growth of parents of children with disabilities in Kosovo, along with challenges in parenting their children, by using qualitative exploration. This study was conducted using a phenomenological approach. The study sample consisted of 10 parents (9 mothers and one father). Data were collected through qualitative semi-structured interviews. Thematic analysis was employed as a method for analysing data. All the transcripts were coded manually. By exploring, and providing context-specific insights into parents' lived experiences, the findings address an important gap in the literature and contribute to a deeper understanding of growth. The findings revealed that parents experienced positive changes in domains of personal strength and relating to others. Social support from various sources emerged as important theme, a factor that contributes to growth. The findings highlight the importance of psychoeducation for family members, as increased knowledge may strengthen their capacity to provide supportive care and improve coping, as well as for general public since it helps reduce stigma. Furthermore, the findings underscore the need for establishing formal support groups for parents of children with disabilities, and this way enhance growth in parents and their well-being.

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Introduction

Most of research seems to have explored challenges of parents of children with disabilities (Broberg, 2011; Smith et al., 2022; Stewart et al., 2017; Tekola et al., 2020), rather than positive aspects of parenting. It is important to note that being a parent with increased levels of personal distress can weaken intervention efforts and negatively affect child's behaviours (Hsiao, 2018). However, more recent studies showed that, despite the strain that parenting a child with a disability brings, parents also experience positive changes and growth in themselves and family (see, e.g., Beighton & Wills, 2019; Sheldon et al., 2021; Young et al., 2020). This phenomenon is defined as posttraumatic growth (PTG) and can be experienced as personal growth in the domains of 'personal strength', 'relating to others', 'new possibilities', 'appreciation of life', and 'spiritual and existential change' (as discussed in Tedeschi et al., 2018).

This study is informed by posttraumatic growth theory that defines posttraumatic growth (PTG) as a positive psychological change emerging from a struggle with highly challenging life events that seriously challenge an individual's assumptive world (Tedeschi et al., 2018). Moreover, the change is transformative and goes beyond previous level of functioning (Tedeschi et al., 2018.). Past research indicates that coping with distress can be an initiation for a process of growth in parents of children with disabilities (see, e.g., PTG in parents of children with Down syndrome; Counselman-Carpenter, 2017). Research seems to support the applicability of the model of PTG as a conceptual framework for understanding the psychological adaptation in parents of children with disabilities and for explaining personal growth in parents of children with disabilities (Young et al., 2020). Variables that correlate with PTG seem to be consistent across cultures (Tedeschi et al., 2018). Perceived social support and peer example were found to be facilitating factors of PTG (Zhang et al., 2015), and to be likely associated with well-being of parents of children with disabilities (McCrossin & Lach, 2023). Moreover, disclosure and social support, can influence PTG in various ways (Tedeschi et al., 2018). As far as sources of support are concerned, parents of children with disabilities can benefit from all support sources (Hsiao, 2018), among which extended family members can be a very important source of support for them (see D'Astous et al., 2013; Lee & Gardner, 2015; Li et al., 2025).

Posttraumatic growth is important considering that it is associated with the well-being of people experiencing it. Facilitation of PTG within the psychological support for mothers of children with autism can benefit the well-being of mothers (Zhang et al., 2015). Therefore, identifying predictors of positive aspects would be beneficial in guiding professionals who provide support to parents of children with disabilities (Beighton and Wills, 2019). Most of literature review related to parenting children with disabilities in Kosovo seems to point to findings regarding challenges of parenting children with disabilities (see, e.g., Kadriu et al., 2026; Retkocer Hoxha & Karovska Ristovska, 2024; Zefi et al, 2026).

This study explores the lived experiences of growth of ten parents of children with disabilities in Kosovo. Using a phenomenological approach, it explores experiences of growth, the meaning parents of children with disabilities give to the challenges they face, and facilitating factors of growth. Acquiring a more thorough understanding of parental experiences is of the utmost value, as it serves as a source of information for policymakers, healthcare professionals, and families. To date, to my knowledge, growth was not explored in the population of parents of children with disabilities in Kosovo, which is an important research gap considering that they may experience PTG in a different way from parents in different cultural contexts. To my knowledge this is the first study exploring growth in parents of children with disabilities in Kosovo. The specific objectives were as follows: (a) to explore

experiences of growth in parents of children with disabilities (b) to explore the facilitating factors of growth.

Methods

This study employed a qualitative research design to explore experiences, meanings, and factors associated with growth in parents of children with disabilities. Qualitative research is helpful in understanding people's unique experiencing of PTG, and in understanding the underlying mechanisms of growth (Tedeschi et al., 2018). Moreover, qualitative studies are also helpful in exploring how different cultures perceive and express PTG (Tedeschi et al., 2018). In the absence of research related to growth in parents of children with disabilities in Kosovo, as a form of qualitative research, phenomenology was selected since it enables learning from the experiences of others (Neubauer et al., 2019). Considering that the goal of phenomenology is to describe a meaning of an experience (Teherani et. al, 2015), phenomenological approach to research was used to explore the phenomenon – in this case, growth from the perspective of parents of children with disabilities and associated factors. Phenomenological research design enabled exploration of unique experiences of growth in the context of challenges in parenting of children with disabilities, identifying sources of social support that contribute to growth, and risk factors to psychological adjustment of parents of children with disabilities. Thematic analysis was employed to analyse data according to commonalities, relationships and differences across a data set (Gibson & Brown, 2009), based on the six-phase framework provided by Braun and Clarke (2006).

Participants

This qualitative study is a part of a larger, mixed-design study on posttraumatic growth in parents of children with disabilities and associated factors. In the quantitative part of the study, 100 participants were recruited from five different diagnostic and therapeutic centers in Kosovo, to complete several questionnaires, among which the Posttraumatic Growth Inventory – Expanded Version (PTGI-X). They were also required to optionally provide their phone numbers in case they would later be invited for a qualitative interview.

Therefore, for this qualitative study, discussed in this paper, from the 100 participants, 10 participants were selected for the qualitative interviews from the groups with high versus low PTGI scores. Beyond PTG outcomes, additional selection criterion were considered to capture variability in parental experiences, such as type of disability of the child, time since the child's diagnosis, and family structure such as nuclear/extended family. These additional criterion were decided based on literature review. In the course of this research, a comprehensive total of 10 participants were actively engaged in interviews ($n = 10$). Within this participant group, 9 individuals ($n = 9$) represented mothers, while one parent constituted the male parent cohort – a father ($n = 1$). Participants ranged in age from 34 to 60 ($M = 43$ years), while their children ranged in age from 2 to 11 ($M = 8$ years). Three parents have children with Down syndrome, five parents have children diagnosed with autism, one parent has a child with a mild intellectual disability, and one parent has a child diagnosed with attention deficit hyperactivity disorder (ADHD). From ten children, four are girls, six are boys. Five parents live in a nuclear family, whilst five parents live in an extended family. The sample was also diverse in terms of geographical location (from three municipalities: Prishtina, Mitrovica, and Peja), and also educational background (from primary school education to higher education degrees). This variability allowed the study to explore the individual variations in parents' experiences, however also to identify common themes. Table 1 provides an overview of participant distribution.

Table 1. *Demographic Characteristics of the Participants (N = 10)*

Participant	Parent's Gender	Parent's Age (in years)	Child's Age (in years)	Type of Disability	Family structure
P1	Mother	52	7	Down syndrome	Extended
P2	Mother	47	8	Mild Intellectual Disability	Nuclear
P3	Mother	34	2	Down syndrome	Nuclear
P4	Mother	34	8	ADHD	Extended
P5	Mother	37	4	Autism	Extended
P6	Mother	35	10	Autism	Nuclear
P7	Mother	43	9	Autism	Extended
P8	Father	36	10	Autism	Extended
P9	Mother	60	11	Down syndrome	Nuclear
P10	Mother	49	9	Autism	Nuclear

Procedure

The participants were recruited in the period of April and May, 2026. Data were collected using semi-structured interviews with parents of children with disabilities. The interview outline was established based on literature review regarding challenges of parents of children with disabilities, posttraumatic growth, and associated factors. Additional probing questions were posed to enable parents to express their unique experiences and meanings, and expand conversations based on what was important to them regarding their child. All ten interviews were conducted face-to-face. Nine of the interviews were conducted in a separate room of respective centers where their children were usually provided with multidisciplinary therapeutic services. Only one interview was conducted at a mother's workplace with her preference. The interviews lasted between 38 and 90 minutes. They were audio-recorded with prior written informed consent that was reviewed and discussed before starting the interview.

Data Analysis

All interviews were transcribed shortly after interviews were conducted, and they were de-identified for identity protection. Thematic analysis was used to analyse data. All the transcripts were coded manually, following the six-phase framework outlined by Braun and Clarke (2006). Through an iterative, interpretive process, codes were grouped and refined into broader themes. Themes were further supported with participants' original quotations. Constant comparison techniques were used to examine the recurrence of information identified across the interviews, and differences within and across participant accounts. Reflexive memos were employed to increase the credibility of the findings.

Ethical considerations

Ethical approval for this study was obtained from the Ethics Committee of the Faculty of Philosophy, University of Prishtina “Hasan Prishtina”, with protocol number [03/1890/1] prior to data collection.

All participants were provided with informed consent prior to participation, via which they were informed about the purpose and nature of the interviews, potential risks, discomforts, and benefits, that their participation is entirely voluntary, and that they can withdraw from study at any moment.

Results

Five major themes identified in this study are discussed in this paper. The first two themes were identified regarding parents’ experiences of growth coexisting with challenges in parenting a child with a disability. And then the three social support themes are discussed as facilitating factors of growth. Several examples of themes and subthemes are provided in Table 2.

Theme 1: Becoming assertive and addressing prejudice.

Several mothers accounted that they have become stronger, emotionally stronger. They further elaborated the theme of strength by explaining that they used to be timid and quiet, and now they are more outspoken, fighters, especially concerning their children’s best interests. This is illustrated in a following quote of one mother (P1): *“just like a flower that comes out of earth, that is how I got the strength. I was myself surprised, how I can go through all of this, you know. I used to be very timid, very quiet, but with birth of my daughter I became very strong, a ‘fighter’, I changed a lot, and now I speak much more”*.

One of the occurring themes in more than half of accounts was facing perceived prejudice from others in their environment. Parents were expressing contradictions within their own account. The way parents described their own growth was that they have become *insensitive* towards prejudices. However, after a more thorough analysis, it seems again that they have become more *assertive* in countering prejudice, rather than insensitive. This can be illustrated with a following quote by a mother (P3): *“Mothers of children with disabilities are definitely heroes. Now I am simply stronger. Earlier I was bothered by other people’s words. Now I am able to stand up for myself”*.

Theme 2: Developed empathy and compassion

Several parents expressed their views that they now have a deeper understanding of the challenges parents of children with disabilities endure, however, also a better understanding of children’s behaviours. They also emphasized their wish to help other parents of children with disabilities, just like they were helped themselves. The father (P8) expressed this view in following terms: *“Earlier, I would feel sorry for a child with a disability. However, I didn’t identify with the parent, until I had my own child with a disability. You see, the family also becomes challenged. Besides that, now I also understand better the behaviours of children with autism”*. Another mother declared (P1): *“Now I think more about children with difficulties. I try to offer my support, like others offered to my child, because now I understand them better”*.

Theme 3: The role of family members in the lives of parents of children with disabilities.

One of the reoccurring themes in several parents’ (mothers’) accounts was an initial denial of the child’s developmental difficulties by family members, even by the child’s father. Their major concern was, when they were faced with denial of the child’s disability by family members, that the child would miss the opportunity for early intervention. It is illustrated in the following quote by mother (P7): *“As a mother, I was hurt, all mothers are hurt if they are not believed. It was clear for me that my daughter had difficulties. I was told not to be upset.*

However, I was, because, whenever I would read about it, the sources said that it was important to intervene early if the child was with autism, in order to achieve something. I was always afraid of this (of being late with intervention). But, they didn't know better". Whilst another mother (P4) complained that it was very hard for her to convince her husband's parents, particularly her mother-in-law, to comply with the limits she would set to her son, (such as decrease his screen-time and sugar-intake, considering that, to her understanding, these would affect his ADHD symptoms). She commented: *"We spoke about it for three or four years in a row, however, she was convinced only after she had heard three psychologists saying the same thing on television"*.

Moreover, if the child already was receiving habilitative services, the denial and disbelief by family members, created a doubt in a parent (mother) whether she made a proper choice on having the child receive therapy. One mother (P5) proclaimed: *"It really bothered me that until my son was officially diagnosed with autism, nobody would admit that he had difficulties. My husband wasn't convinced that the therapies were helping him. Even though I could see improvements in my son's development, I was worried then that I wasn't making proper decisions for him"*.

It is important to note that most parents, in spite of the occasional challenges they faced with convincing their family members that the child had difficulties, they still emphasized that they considered family members an enormous source of practical, financial (for medications, clothes), and emotional support.

Practical support was described, including helping with transportation of their child to school or to therapy, or contributing to their child's development, illustrated in the following quote: *"I have a lot of support. My parent-in-laws often take my son to spend the weekend with them. They encourage him to communicate and use speech, and spending time with grandparents, helps him grow and become emotionally stronger"* (Mother, P10). Another mother (P3) expressed the importance of support from her husband, in following terms: *"we are united in achieving solutions ... there is no such thing in my family as ME, ME, it is always WE"*.

Regarding emotional support from family members, several parents emphasized the importance of the words of encouragement regarding their child and the child's future, as described in the following quotation: *"My mother provides me with emotional support, encourages me, by saying to me that I must continue trying further, to take care of my son, to continue living, and not give up"* (Mother, P2).

Contrarily, another parent (father, P8) shared his hesitation to express his needs for emotional support and to receive it from his nearest family members. However, he found an alternative way to self-disclose and help himself instead: *"In the beginning, I couldn't open this topic (about child's condition, autism) to my wife, we didn't speak about it because I knew she would become sad. She had her own dose of sadness...I didn't want to add mine. Now I speak to my wife more about it. My mother was also sad about it. Therefore, to tell you the truth, I would express myself at my father's grave. I felt like boiling inside ... with pain... I could cry or something, and I didn't want anyone to see me. And then I would come back home 'reset' (said it laughingly)."*

Theme 4: the role of friends and colleagues in the lives of parents of children with disabilities. Many parents' accounts revealed that friendships were an important resource for them that helped them with coping with struggles in parenting children with disabilities, as illustrated in the following quote (mother, P10): *"Friendship is like therapy"*.

One of the changes that some parents (although less in number) experienced and reported was the tendency for self-isolation. However, more parents noticed in themselves that, due to parenting a child with a disability, they became more selective in socializing: either socializing with friends who can in some way be helpful, or who are not prejudicial. Interestingly, most of

them pointed out that the most of their friends had children with developmental difficulties as well, or with problems at school. The following quote illustrates this: *"Luckily, when my son started to attend school, we have been four parents that have children with special needs, and we helped each other a lot regarding emotional difficulties. The challenged/tried one understands you better."*

One of the subthemes that occurred was the importance of self-disclosure (meaning, regarding having a child with disabilities) in order to be able to utilize support from their friends or colleagues. A mother (P6) explained: *"If you explain your situation, there is no colleague that will not support you. In other words, when you declare the situation you have at home, the work environment will also change. We should not be afraid whether we will be seen as victims or someone to pity, but should create mechanisms outside of our home to be helped with coping in our daily life"*.

Contrary to other parents, another parent (father, P8), for the same reason, which is, not wanting to be 'identified as a victim or as someone you feel sorry for', chose only partial disclosure. He reported: *"I didn't share much with other people, such as colleagues, the fact that my son is with autism. I didn't want to stand out. It can happen to anyone"*.

Theme 5: the role of centers in the lives of parents of children with disabilities and the need for professional support for parents

One common theme that occurred in the parents' accounts was the role of centers in supporting them in parenting children with disabilities. Apparently centers provide them with professional help for their children, knowledge regarding helping their children. As one mother (P9) described her experience of attending activities with her daughter at the Down Syndrome Kosova center in a following way: *"The center gives you an opportunity to bring children here for activities since a young age and then they achieve more. I learned a lot here."*

Based on parents' account, centers also provide an informal parent-to-parent support. A mother (P6) whose daughter is with autism describes how meeting parents with similar experiences can be of enormous help: *"There is information you can learn only from other parents of children with disabilities. This is not something that you can learn from books or from movies. Only a parent that has experiences like this for 24 hours a day can provide you with such an advice"*. The way another mother (P3) of a child with Down syndrome explained the importance of the center for her is illustrated in the following quote: *"If there is a place where I feel like at home, then it is this center. You see, we have become like a family here. We support each other. It is because we have a same problem. You cannot tell about your problems to a mother who has a child with a typical development. Because their problems are different."*

Attending centers seemingly also provided them with opportunities for comparison: *"Earlier, I've been mostly staying home. Now I go out more, I communicate more to people. It helped me cope more easily, seeing other people coping with the same issues"* (Mother, P9).

An important theme that emerged from the parents' accounts was their need to be provided with a structured professional support, not solely to their children, illustrated with a following quote: *"There should also be centers for mothers"* (Mother, P3). Another mother (P6), whose child is with autism, declared: *"Just like there is a place for our children to be treated, we, the parents, also need a treatment like our children do. We urgently need a place like that for ourselves"*.

Table 2. *Examples of Themes, Subthemes and Quotations.*

Theme (examples):	Subtheme (examples):	Quotations (examples):
Developed empathy and compassion	Understanding parent; Understanding child's behavior.	"I earlier heard about Down syndrome, but didn't know what parents had been going through".
The role of family members in the lives of parents of children with disabilities.	Denial of difficulties in development; Lack of knowledge. Practical, financial, emotional support.	"As a mother, I was hurt, all mothers are hurt if they are not believed. It was clear for me that my daughter had difficulties ... But, they didn't know better". "I have a lot of support. My parent-in-laws often take my son to spend the weekend with them ... spending time with grandparents, helps him grow and become emotionally stronger".

Discussion

The findings of this study indicate that parents of children with disabilities experience personal growth despite the challenges associated with parenting a child with a disability. This finding supports the findings of studies on presence of PTG in parents of children with disabilities in other countries, such as studies reported by Zhang et al. (2015), or by Counselman – Carpenter (2017). The way most of the parents described their personal growth was that they became emotionally stronger and 'fighters', in a way that they became much more assertive than before, and able to face with perceived prejudices. This study shows that these parents apparently face social challenges, which is in line with another study that showed that parents of children with disabilities often face with social processes that may affect their emotional functioning in a negative way (Broberg, 2011). However, parents also reported higher self-esteem in pursuing what they thought was best for their child, in spite of perceived discouragement from the others in their environment, by being able to ignore prejudicial comments, or by responding assertively when necessary, in various parts of society. The above-mentioned changes, as part of personal growth, are in line with the description provided by Tedeschi et al. (2018) that changes can also happen in one's behaviours or attitudes in relating with others, and that these changes can be connected to changes in personal strength. Another theme that emerged in the accounts of parents when describing growth, was higher level of empathy for others, compassion, and a more active engagement in helping others with similar struggles, a theme that is consistent with findings from a study by Beighton and Wills (2017). Moreover, being more compassionate reflects the experience of positive changes in relationships (Tedeschi et al., 2018). Apart from themes regarding perceived changes in terms of personal strength and relating to others experienced by parents of children with disabilities, important themes emerged regarding social support.

Family, whether nuclear or extended, was mentioned as a very strong social support source, in terms of practical, material, and emotional support. This type of support is in line with several types of support provided by extended families, identified in the systematic review and meta-synthesis reported by Li et al. (2025). Moreover, this study's findings about family social support importance are consistent with the literature showing that perceived family support and acceptance also play a role in how parents face stigma (Tekola et al., 2020). However, one important subtheme that emerged in the accounts of parents of children with disabilities, especially from parents living in extended families, was a tendency of family members (even of partners-fathers) to react with denial of the child's difficulties in development. This further led to another important subtheme, which is unnecessary doubts about the importance of early intervention. Moreover, insufficient understanding of the child's disability and diagnosis and about management of the condition by the members of extended family, based on several mothers' accounts, gave the mothers an additional burden of having to explain about the disability to the rest of the family. The parents explained that the denial or minimization of the child's condition among family is primarily attributable to their lack of knowledge, which is in line with the study that showed that factors related to knowledge may impact how extended relatives respond to autism diagnosis (see Li et al., 2025), and that a good understanding of a disability can strengthen grandparents' engagement that can be beneficial for the entire family (D'Astous et al., 2013). The lack of understanding of the importance of early intervention is consistent with the findings of previous studies that emphasize the importance of educating grandparents by professionals regarding their grandchild's disability (see, e.g., Lee & Gardner, 2015).

Another reason for not discussing openly about the child's condition among family members may be protective buffering which is a coping strategy that involves hiding worries from one's partner (Winterheld, 2017), a strategy clearly explained by the father (P8) who rather expressed himself next to his father's grave than to his nearest family members. A theme regarding the role of friends and colleagues reveals friendship as an important support source that contributes to growth, which is consistent with the findings of a phenomenological study on PTG in mothers of children with autism that reported the importance of peer social support as a facilitating factor of posttraumatic growth (Zhang et al., 2015). However, this study also reveals about the selectiveness of parents in making friends, mainly friends who also have children with disabilities, which supports the findings of earlier studies that some parents feel the need to identify with others in similar situations who would understand them (Smith et al., 2022). Moreover, this perspective was elaborated by Tedeschi et al. (2018), according to whom, listeners, especially if they have also experienced a similar event, may offer different views on the event, or serve as role models.

Additional subthemes were identified in the lived experiences of parents that seem important for utilizing social support from friends and colleagues. Several parents mentioned a subtheme of 'being perceived as a victim' (the expression used by participants themselves) towards which parents had different reactions. This mirrors the findings of previous studies that caring for a child with chronic conditions (including neurodevelopmental disorders) challenged the parents' identities (Smith et al., 2022), and is in line with the view that a person wants to be recognized as an individual without the label of a victim, considering that the person does not want to be defined by an event, because PTG is not about the event, but about how the person lives in its aftermath (Tedeschi et al., 2018). Interestingly, some parents (mainly mothers in this study), because they didn't want to be considered 'victims', decided to disclose their child's diagnosis and the challenges they came across with in caregiving of the child. Therefore, being able to overcome internal barriers and to self-disclose, further enabled parents to receive support for themselves, such as from colleagues. It is important to note that

constructive self-disclosure is considered an important element in PTG facilitation, whilst the decision to self-disclose can be a form of PTG (Tedeschi et al., 2018).

Another very important theme that emerged in parents' accounts has to do with identifying centers, where their children attend therapies for enhancing their development, as crucial social support sources. Apparently these centers provide parents with opportunities for socializing with other parents of children with disabilities, for feeling understood and accepted, that is in line with a study by McCrossin & Lach (2023) that reported about the importance of sharing one's story and being heard in the peer-to-peer parent support networks. Sense of connectedness to others and sense of belonging to a community are found to be important in promoting PTG (Tedeschi et al., 2018). Moreover, the centers also provide parents with knowledge, and an increased sense of self-reliance, which is a way posttraumatic growth is experienced (Tedeschi et al., 2018).

The findings from the interviews revealed the necessity for a structured, formal, and professional support for parents. This view is supported by earlier studies that reported about the importance of professionally supporting parents in reducing their stress (see, e.g., Hsiao, 2018; Smith et al., 2022).

Conclusion

This study examined the lived experiences of growth of Kosovar parents of children with disabilities, identifying five themes: becoming assertive and dealing with prejudice, developed empathy and compassion, the role of family members in the lives of parents of children with disabilities, the role of friends and colleagues in the lives of parents of children with disabilities, and lastly, the role of centers in the lives of parents of children with disabilities and the need for professional support for parents. Several shared subthemes across the different themes were identified, such as socializing with other parents who have children with disabilities, refusing to be perceived as a victim, importance of self-disclosure.

The analysis highlights the potential of parents to experience growth, in which social support from various sources plays a crucial role. For a more widespread impact, psychoeducation on disabilities and their management needs to be provided both, by professionals, and via media, not only for parents and their families, however, also for general public. Increased knowledge and understanding reduces stigma, and helps parents better utilize social support sources.

Formal supportive groups need to be organized, instead of using informal opportunities, possibly in existing centers, for parents to be able to disclose their experiences, explore their fears and perceived benefits that would promote PTG, and would further enhance parents' psychosocial functioning. Families could also benefit from family therapy practices to enhance communication between family members, emotion sharing and this way impact mutual PTG.

The study has limitations. A small sample of parents, predominantly with mothers, suggests the need for future studies to examine the potential gender and culturally relevant differences in experiencing growth and in perceiving social support.

Conflict of interest

None.

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